

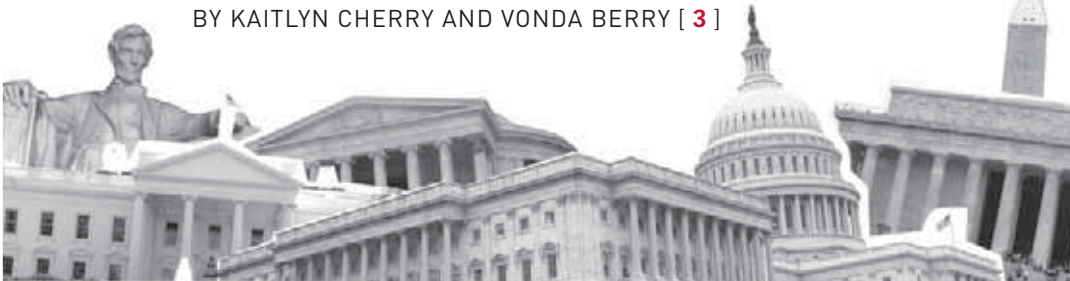
# BREAKING GROUND



ERIN BRADY WORSHAM  
TAKES TO THE SLOPES [9]

## MOM AND DAUGHTER TEAM JOIN OTHERS IN REPRESENTING TENNESSEE IN NATION'S CAPITAL

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OVERWEIGHT PREVENTION  
FOR CHILDREN  
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COUNCIL'S NEW  
EXECUTIVE COMMITTEE [19]

TENNESSEE  
COUNCIL  
  
DEVELOPMENTAL  
DISABILITIES

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**Cover photos:** *Top, left:* Kaitlyn Cherry; *top, right:* the Cannon House Office Building (photos by Gina Lynette)  
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*Bottom, right:* Paul Marchand, Disability Policy Collaboration (photo by Gina Lynette)  
**Addendum:** In Issue #35, photos on pages 18-19 by Kate Heyden.

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## MOM AND DAUGHTER TEAM JOIN OTHERS IN REPRESENTING TENNESSEE IN NATION'S CAPITAL

BY KAITLYN CHERRY & VONDA BERRY



### Kaitlyn's perspective:

From March 1 through March 3, my mother and I attended the Disability Public Policy Seminar in Washington, D.C. We went to help represent The Arc of Tennessee with other members of our State chapter. I attended many informative sessions speaking about the legislation going through at this time. There were over 600 participants at this particular meeting, and a variety of sessions to attend.

We attended sessions on the Americans with Disabilities Act (ADA), and Social Security. The seminar lasted from Sunday morning to Monday evening. On Tuesday, we visited Capitol Hill where we met with Legislators. I attended a breakfast with Tennessee's U.S. Senators, Lamar Alexander and Bob Corker. My mother and I, plus three other ladies from Tennessee, met with Senator Alexander's aide.

After lunch, we met Representatives Marsha Blackburn and Lincoln Davis. We discussed housing issues with Representative Davis' aide. Throughout all of these meetings we were discussing important legislation that is presently before Congress. I personally feel that everything done and discussed was very productive. This whole trip meant a lot to me because it was about issues that I feel are necessary to discuss, be passed as legislation, and enforced afterwards. I was particularly interested in the legislation regarding education and restoration of the ADA, since I am a student who is blind and who will be graduating from Lincoln County High School in May of 2008.

*Kaitlyn Cherry is a graduate of the 2006 Tennessee Youth Leadership Forum*

Top, left: National Museum of the American Indian Top, right: Sue Lin, AUCD, and, right, Laurel Ryan, Boling Center, Memphis.  
Bottom: Deana Claiborne, United Cerebral Palsy of Middle Tennessee. All photos by Gina Lynette.

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#### **Vonda's perspective:**

It was thrilling to be in the nation's Capital and to be a part of such a wonderful group of people. The speakers were fantastic and so willing to share their knowledge and expertise in meeting with U.S. Legislators. From a mother's view, it was even more exciting to watch my 16-year-old daughter interact not only with other self advocates and advocates, but with the legislative aides as well. Kaitlyn is proof positive that if all the supports, accommodations/modifications and training are in place, any student can and will be a thriving success.

Kaitlyn stressed the importance of the restoration of ADA and what it means to people who have a variety of disabilities...whether intellectual, physical or developmental. The legislative aides realized that, in approximately one year, Kaitlyn will be a voter. Was I proud? Of course! I got to see my little girl—who has turned into quite the young lady—educate and advocate for all who have a disability, and support those issues up for discussion in Congress that our friends, neighbors and family members who have disabilities encounter on a daily basis.

*Vonda Berry is a graduate of the Partners in Policymaking™ 1999–2000 class.*

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1 Congressman John J. Duncan, Jr. with Stephanie Brewer Cook 2 House Majority Leader Steny Hoyer 3 National Museum of the American Indian  
4 Kaitlyn Cherry 5 Library of Congress. All photos by Gina Lynette.

# SPORTS 4 ALL, THE GOAL SINCE 2005

BY SARA KOPPELMAN

The Sports 4 All Foundation (S4AF) is changing lives for athletes with disabilities nationwide. Founded by Kris Salisbury, Sports 4 All exists to fill a financial void and correct misconceptions. Ms. Salisbury and her husband Dennis have a daughter, Erica, who has Down syndrome. They also own two retail sporting goods stores, Neptune in Nashville and Steep and Deep in Birmingham, Alabama. Over their 30 years as retail store owners and community volunteers, the Salisburys have witnessed the lack of appropriate sporting equipment and funding available to athletes with disabilities. The Sports 4 All Foundation provides a solution to this problem.

"My love for my 22-year-old daughter Erica is the reason I started S4AF," says Ms. Salisbury. "People with disabilities need to get out and experience what the able world often takes for granted – self worth, team participation, accomplishment and success. Through our programs, we enable those with disabilities to be active and involved in sporting events using the best gear we can offer. I was amazed when attending Erica's sporting events to see athletes without suitable shoes to run in, helmets and mittens to snow ski or snowboard in, or protective gel gloves for wheelchair users."

The Foundation offers three programs: Equipment Endowment, Enduring Athletes and Sport Support. Equipment Endowment donates gear or provides funding for it to athletes in need. Enduring Athletes provides athletes with the resources needed to travel and participate in sports activities, and Sport Support matches funds raised by the group up to \$500.00.

**"Wow, now I have equipment like everybody else!"**

*Gail, a young woman as she was being outfitted with new equipment*

S4AF is unique in its operational sustainability. Revenue is generated through donations of sporting equipment (from individuals, manufacturers or retailers) and is given to an athlete in need or sold. This innovative approach to generating revenue offers a measurable full circle benefit. For example, the donor takes a tax deduction; S4AF generates revenue to further its mission; and the purchaser receives the product at an unbelievable price. When the donated goods are not appropriate for the needs of the athlete(s), the Foundation will provide funding or find the gear needed for safe and enjoyable competition.



Sara Koppleman. Photo credit: Kris Salisbury.

Camps and recreation programs for children and young adults with cognitive impairments recently received sporting equipment to enable those programs to exist with a sports component. Balls, bats, frisbees and jump ropes are among some of the pieces of equipment given to these local programs.

**"I can accomplish anything after this!"** *Stephen, a young man with Cerebral Palsy, after safely experiencing his dream of snowboarding with the equipment and clothing from Sports 4 All*

Most recently S4AF partnered with Make A Wish Foundation® of Alabama. The Make-A-Wish Foundation® grants the wishes of children with life-threatening medical conditions to enrich the human experience with hope, strength, and joy. Because of this partnership a young man with cerebral palsy will achieve his dream of snowboarding. The athletic equipment provided by S4AF will keep him safe, dry and warm, so he can compete to the best of his ability.

Dennis, a director of Special Olympics in a Tennessee county, explains what the Foundation has meant to him. "The Sports 4 All Foundation has provided us with the equipment and support our special athletes need to compete. My team and I can plan the sporting events and in the past had a financial burden to provide equipment for them. The Sports 4 All Foundation has eradicated that burden and supports our athletes so they can compete in and enjoy their athletic achievements".

For more information or to request an application and guidelines for support, visit The Sports 4 All Foundation online at [www.s4af.org](http://www.s4af.org).

*Sara Koppleman is program and development manager for S4AF.*





# UNEQUAL PROTECTION...UNEQUAL JUSTICE?

## (PART ONE)

BY ALICIA CONE, PH.D.

As Director of JP Das Developmental Disabilities Centre and of the John Dossetor Health Ethics Centre, Dr. Richard (Dick) Sobsey has written extensively

about violence against people with disabilities. In 1997, Dr. Sobsey wrote that civil rights consist of two essential parts: equal protection and due process. The right to equal protection of the law came to U.S. citizens with the ratification of the 14th Amendment in 1868, which declared that no state may "deny any person within its jurisdiction the equal protection of the laws." In regard to crime victimization, its meaning is clear: efforts to deter and prevent crime must attempt to protect all citizens on an equal basis, and a crime committed against any citizen must be investigated and prosecuted as vigorously as it would be if the crime were committed against any other.

Likewise, sentencing of offenders must be based on the seriousness of their crimes and not the status of their victims. Sadly, the promise of equal protection of the law has never been fully achieved for all citizens, and no group of citizens has been more consistently deprived of equal protection than people with intellectual and developmental disabilities (ID/DD).

Most criminal justice personnel, regardless of their roles in the system, do not know what intellectual and developmental disabilities are, let alone how to recognize that a person might have an ID/DD. Criminal justice personnel often have not developed the skills necessary to effectively work and communicate with individuals with disabilities. Leigh Ann Davis, who has worked in the area of criminal justice and disability since 1994, has stated that without accurate identification of intellectual and developmental disabilities among victims, witnesses and defendants, people with ID/DD will not have the support needed to fully participate as equal citizens in the criminal justice and legal system.

Individuals with disabilities are more likely to be the victims of a crime than people without disabilities. A 1998 estimate by the U.S. Department of Justice, Office for Victims of Crime revealed that people with developmental disabilities are at a four to ten times greater risk of becoming a crime victim than people without a developmental disability.

"People with ID/DD are more vulnerable to all types of victimization, including neglect, financial abuse, physical abuse, sexual abuse and rape," said Ms. Davis. "Victims with ID/DD are often alone, without the aid of any practical coping tools or assistance, after victimization occurs. Or the person may not realize they are or have been victimized, and therefore, will not report the crime to anyone."

Dan Sorenson has been active in advocacy groups for people with developmental and other substantial disabilities for over thirty years, and founded and chaired the California Coalition on Crimes Against People with Disabilities. In 2000, both Mr. Sorenson and Ms. Davis identified issues that need to be addressed before people with ID/DD come into contact with the criminal justice system (CJS) as a victim or witness. How can victim assistance and disability organizations work closely together in an effort to reach out to victims with ID/DD, and how can the various state, county, and local agencies responsible for helping victims collaborate? What resources or treatment options, if any, are available for victims with ID/DD in local communities, such as counseling services, rape crisis services, support groups, behavior support services, and self protection training? What types of abuse or victimization are considered criminal in nature when the victim has ID/DD?

And finally, what needs to be done to address the widespread belief that the testimony of victims or witnesses with certain disabilities will not stand up in court because their testimony is "unreliable." Mr. Sorensen points out that this belief among prosecutors, jurors and judges makes these cases hard to win, and that this belief is more a part of the pattern of stereotypes and discrimination than a reflection of reality.

People with intellectual and developmental disabilities are a small but ever increasing percentage of the offenders in the criminal justice system. Dr. Joan Petersilia is a Professor of Criminology, Law and Society in the School of Social Ecology, University of California, Irvine (UCI), and has directed major studies in policing, sentencing, career criminals, juvenile justice, corrections, and racial discrimination. According to Dr. Petersilia, "People with developmental disabilities are estimated to comprise 2% to 3% of the general population, but represent 4% to 10% of the prison population, and an even higher percentage of those in juvenile facilities and in jails."

Dr. Petersilia says that many, if not most, people with intellectual disabilities and developmental disabilities who become involved



with justice authorities have mild disabilities that are not easily recognized by people who are not specially trained to recognize them. As a result, most people with ID/DD proceed through the complex criminal justice system without any special accommodations to help them negotiate the system.

In 1985, a law professor, James Ellis, and a special education professor and lawyer, Ruth Luckasson, wrote a monograph entitled *Mentally Retarded Criminal Defendants*. This became the seminal publication of its time. Their monograph had profound effects on advocates and professionals in the field of disability, not the least of which was Robert Perske, who has become one of the world's staunchest advocates for people with intellectual and developmental disabilities who are coerced into confessing to crimes they did not commit. He has directly and indirectly followed over one thousand of these cases.

In 2003, Mr. Perske wrote the following about this monograph, "It became the groundbreaking document of the century. It covered from every angle the crucial issue of persons with mental retardation and the criminal justice system. I liked this monograph so much because it set forth for the first time a list of characteristics that people with mental retardation may possess—characteristics that render them utterly vulnerable in police stations and courts."

Some of these characteristics include:

- relying on authority figures for solutions to everyday problems,
- the desire to please people in authority,
- the inability to abstract from concrete thought,
- watching for clues to answers from interrogators,
- bluffing greater competence than one possesses,
- a quickness to take blame,
- short attention span,
- problems with receptive and expressive language,
- the longing for friends,
- relating best with children and older persons,
- plea bargaining by accomplices (to get lighter sentences by testifying against the person with a disability),
- an all-too-pleasant façade,
- abhorrence for the term mental retardation,
- real memory gaps,
- impaired judgment,
- an inability to understand court proceedings,
- uncontrolled impulses,
- an unsteady gait and struggling speech, and
- exhaustion and surrender of all defenses.

When a person with an intellectual or developmental disability comes into the criminal justice system—designed to be complex and intimidating in order to deter citizens from breaking any laws—the experience of the person, as described by Dr. Petersilia, is of an individual who does not usually understand his/her rights, frequently waives those rights, is usually in jail pre-trial, when

questioned by police will often give answers he/she believes the police want to hear (rather than correct answers), are less able to assist with their defense during court proceedings, confess more readily, provide more incriminating evidence to authorities, and are less successful at plea bargaining.

Ms. Davis states that it is clear that offenders with ID/DD are often without appropriate services or programs to help them stay out of the criminal justice system in the first place, and assist the person once he or she becomes involved in the criminal justice system.

Further, Mr. Perske believes that it is undeniable that persons with disabilities can be the easiest to bear false witness against, the easiest from whom to coerce a confession, the easiest to demonize in the press, and the easiest to ignore when it comes to fighting for constitutional rights.

Advocates in this area, specifically, Ms. Davis, Jeri Houchins, Frank Laski and Kirsten Keefe, The National Advisory Group for Justice and Dr. Petersilia have made the following recommendations to ensure people with ID/DD do indeed have equal protection and equal justice.

1. Justice-related education for people with ID/DD and their families or care givers must be increased. People with ID/DD must have access to education that enhances their ability to protect themselves from criminal victimization, avoid possible criminal activity, avoid getting into legal trouble, know what to do if he/she does get into legal trouble, learn what and who is safe, talk to police officers, and to protect their rights as citizens. If they do become involved with the criminal justice system, they and their families need to better understand their legal rights, including those that can be requested under the Americans with Disabilities Act (ADA).
2. Professionals in the criminal justice system must receive training on how to identify someone with a disability and know the most appropriate placement/treatment available to the individual. The ADA provision calling for "reasonable accommodation" has been interpreted by the Congress and U.S. Department of Justice to require training for police so they recognize disabilities, respond appropriately, and provide services to persons with disabilities in a non-discriminatory manner. As a matter of public policy, police officers should be trained to recognize when someone has a disability and how to address, communicate with, and work with individuals with disabilities. A special component can be added to the training police officers receive prior to certification and as part of their in-service training.
3. Research is needed to validate and specifically pinpoint the most effective types of services or programs for offenders with ID/DD.
4. Appropriate sentencing options must be developed, including community-based rehabilitation programs, for offenders with ID/DD.
5. Advocate through circles of friends, learning the effectiveness of this strategy and how it can be used to support others.

*Continued on page 8*

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6. Provide legal advocacy for persons with disabilities. This means examining cases in which there were violations of the ADA and advocating for change, including changes in state legislation, to strengthen protections for persons with disabilities.
7. Provide the proper supports to a person with ID/DD who is involved in the CJS. For example, a witness without an advocate assistant is often unable to understand the questions being asked and investigative information is lost.

Do these national findings parallel events and experiences here in Tennessee? Unfortunately, the answer is yes. In the next issue of *Breaking Ground*, we will explore this topic from our own State's perspective.

Alicia Cone is project research and development coordinator for the Council on Developmental Disabilities.

#### Further Reading

If you are interested in reading any of the source material used in this article, the references are listed here.

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## BOOK REVIEW BY CHRISTINA CLIFT

Denise Mercado, *They Created Us: Special Education, Medicaid Waivers, EPSDT, Independent Case Management—A Family's Journey Through a Bureaucratic Maze!* (Bloomington, IN: AuthorHouse™, 2006). Softcover, 315 pages. ISBN: 9781425970703

Every parent has high hopes for his or her children and spends a lot of time imagining what the future is going to be like for them. When a child is born with developmental disabilities, or develops them later in life, a parent's hope is changed into a need for action and support that's not always available.

Denise Mercado knows all about that sudden shift from normal parent to activist. Her son, Danny, contracted a rare form of meningitis when he was six months old, which led to cerebral palsy and other severe health and developmental issues. Danny has never spoken, walked, or done any of the things most children do.

In the beginning, Ms. Mercado and her husband relied on people in their community to help them care for Danny. As time went on, this military family realized they needed more assistance and found themselves mired in bureaucracy, frustration and funding dead-ends.

They were given incorrect information, not made aware of programs that could help them and denied support that, by law, should have been available to them. The more they learned about the way children with disabilities are treated, the more they realized their story was not unique.



"The bureaucracy, in its wisdom, operates through committees and unending meetings," Ms. Mercado writes. "But change will only take place when the bureaucracy takes the time to listen to the people it serves. The bureaucracy must be willing to meet families where they are. It must be willing to leave the state capitol and meet with families in their homes and observe their surroundings and the sacrifices they make and the struggles they endure."

This heart-wrenching book describes the struggles of the Mercado family and others who have children with disabilities in North Carolina in great detail. In fact, there is so much detail, so many long quotes from e-mails and reports specific to the situation in North Carolina, that it might not be as useful to parents outside of North Carolina.

Still, it is very effective as a guide for showing how one family tried to work through the system, its successes and failures, and all the roadblocks along the way. This book will outrage people who care about the treatment of people with disabilities in America, and should also inspire them to fight for their own children as Ms. Mercado and her compatriots have fought for theirs.

Christina Clift is a member of the current Partners in Policymaking™ class and is an independent living specialist/consumer advocate with the Memphis Center for Independent Living.



# ERIN BRADY WORSHAM TAKES TO THE SLOPES!

BY NED ANDREW SOLOMON

9

*Portions of this article appeared originally in the Tennessee Register.*

Erin Brady Worsham is an oft-published writer, an accomplished artist, a sought-after speaker, and a loving wife to Curry and mom to Daniel.

This past March 19th, she added another role to her extensive résumé: downhill skier. Oh, and lest we forget to mention, twelve years ago, Ms. Worsham was diagnosed with ALS, or amyotrophic lateral sclerosis, also known as Lou Gehrig's Disease. Having ALS means she has lost, slowly over time, her speech, her ability to breathe independently, and the functionality of most of her body.

Ms. Worsham has around-the-clock care, a power wheelchair to move, a respirator to breathe and an augmentative communication device linked to a computer to talk, write, inhabit the Internet, and create her gorgeous, detailed artistic statements. She also has a razor-sharp intellect and a positive attitude that never quits, which is a major part of the reason she decided to go on this daring athletic adventure.

"Curry and I have seen a lot of wonderful people come and go in the ALS community," said Ms. Worsham. "My friend, Kathie Hormby, who had ALS longer than me, passed very unexpectedly last year. She was a gutsy dame and would've done this in a heartbeat. So, too, would our friend, Jane McEvoy, who passed from cancer over five years ago. So we three are going to do it together. I'm going to have Curry put their names on my shoulders and we're going to go down that mountain together, in spirit. I hope one of them knows how to ski, because I sure as hell don't!"

About this point, you're probably thinking, "Wheelchair? Respirator? Downhill skiing?" Enter the Bretton Woods Adaptive Program in New Hampshire, an entity created to give individuals with all kinds of disabilities the skiing experience by using extensively trained instructors and adaptive equipment.

The idea hit about a year ago, while Ms. Worsham was watching an alpine skiing event during the Winter Olympics. "For someone who spends all their time sitting still in a wheelchair, watching something like Alpine Skiing can be mesmerizing," said Ms. Worsham "It's not just the speed, it's the power. These ski racers, especially those who race the Downhill and Super-G, must have incredible power in their legs to hold their line down the mountain. Not having any muscle in my legs, I admire that. They can reach speeds of 80 mph.

"Even more than power, it takes courage. I admire that too. I have no wish to go that fast myself, but it's exciting to hitch a mental ride down the mountain with these guys."

Understandably, there was a great deal of preparation for Ms. Worsham's actual downhill skiing adventure, spearheaded by Cris Criswell, formerly the acting head of the adaptive program, and Sandy Olney, the current director. The first day at Bretton Woods included a "dry run" at the base lodge. "Every detail was addressed," said Ms. Worsham. "These people are about safety. They don't want any surprises."

Ms. Worsham was shown two different models of bi-ski, a small sit-up sled on two runners. Unfortunately, neither one offered her required head support. Fortunately, this is a family that has become masterful at problem-solving and quick, on-the-spot fixes. "Curry suggested

bolting the headrest from my wheelchair to the back of the bi-ski seat," said Ms. Worsham. "They brought in their tech guy, templates were taken, plates were made and it happened. Other volunteers were on hand to help with the transfer. Then Curry lifted me into the bi-ski and I was belted into place."

Finally, it was time for the trip down. "My paralyzed body moved forward naturally into the turns," said Ms. Worsham. "Over and over inside my head, I thought, 'Dear God, dear God, dear God, I can't believe I'm here!'"

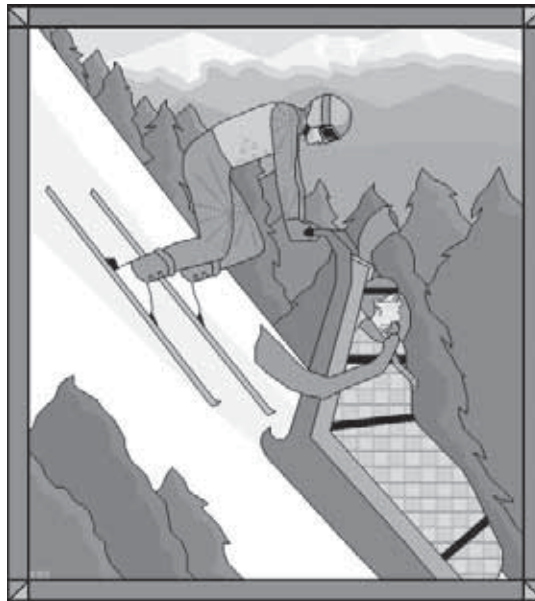
So smooth sailing, um... skiing, until Ms. Worsham's ventilator alarm went off, signaling a low battery—way ahead of schedule. In response, Ms. Worsham and her tetherer picked up the pace, which

created a bumpier ride, and caused Ms. Worsham's head to pop out of its secured mooring. "Three people converged on me and, in under a minute, fashioned a chin strap attached to my head band out of duct tape," she said. "What these people can do with duct tape is amazing!"

To save even more precious breathing time near the end, the tetherer took a direct line toward the bottom of the hill. "What a rush!" exclaimed Ms. Worsham. "They rolled me back into the base lodge and Curry ran in with the power cord for the wall. As he plugged me in, I saw a message I had never seen on my vent before: 'battery empty'. Ask me if I believe in angels."

And just for the record, is this the start of a long line of "gotta do's before I die" for Ms. Worsham? "I have no plans to take up sky diving or water ballet, but I'm keeping an open mind," she said. "My hero, Dr. Stephen Hawking, who has had ALS for some 40 years, is making plans to go into space. Looks like the sky's the limit!"

*Ned Andrew Solomon is the director of Partners in Policymaking™*



"Go Fast" by Erin Brady Worsham

# WATCH YOUR LANGUAGE:

## “MENTAL RETARDATION” MAY BE ON ITS WAY OUT

BY BETH HOPKINS

*“Changing the word could possibly make it better....But also you [have] to change the attitudes; because if the attitudes [are] not changed, the word is not really going to matter.”*

*– Lucius Mangrum, Self-Advocate*

The name “mental retardation” and the designation “mentally retarded” may soon become obsolete descriptors for people with certain types of disabilities. The American Association on Mental Retardation (AAMR) is now known as the American Association on Intellectual and Developmental Disabilities (AAIDD). The AAIDD also has changed the name of one of its major journals to reflect the new name of the organization.

The Board for The Arc of Tennessee (formerly the A.R.C., or Association for Retarded Citizens) has followed suit, replacing “mental retardation”, and like terms, with the term “intellectual disabilities” in all of their bylaws, as well as in their public information literature. The acronym that used the term “retarded” has been gone since 1992.

Similar changes are beginning to ripple through disability-related language elsewhere. The State of Connecticut recently renamed one of its departments to denote that it serves people with developmental disabilities, removing the term “mental retardation” from its title. Massachusetts, through Representative Michael Costello and his staff, also is working for a name change for its Department of Mental Retardation. Adam Martagnetti, chief of staff for Rep. Costello, says, “It’s pretty obvious when you listen to the people receiving the services that the stigma [associated with the term “mentally retarded”] is something they don’t like.”

Advocates with and without disabilities are glad their voices are beginning to be heard. In popular speech, “retarded” has been transformed from a diagnosis into an insult. Think about how many times you have heard people associate “retarded” with something far less than positive or desirable. Now imagine that term was part of a diagnosis that applied to you. That is the case for many people who no longer want such negative labels attached to themselves and their identity.

Walter Rogers, executive director of The Arc of Tennessee (ArcTN), suggests that the only way for the perceptions about people with disabilities to change is for the language to change, from the top down. “The use of outdated words and language to describe people with disabilities continues to perpetuate old stereotypes. It is extremely important for elected officials, others in leadership roles, and the media to portray people with disabilities realistically and with sensitivity.” He also notes our personal responsibility to

monitor language, for ourselves and those around us, in order to preserve dignity and promote community.

No one can deny that there are certain harmful characterizations associated with being known as “mentally retarded”, but there are some misgivings about finding a sweeping replacement for the term. A change in terminology may create confusion for those seeking services. For example, would someone who was considered “mentally retarded” be considered “intellectually disabled” also? Exclusion is a concern also. If the name changes,

March 23, 2007

### Press Release for the Self-Advocacy Organization, Arkansas People First

On Tuesday, March 20, the General Assembly passed the preferred language bill in Arkansas, SB704. The following is an excerpt from the bill sponsored by Senator Tracy Steele:

“The General Assembly recognizes that language used in reference to individuals with disabilities shapes and reflects society’s attitudes towards people with disabilities. Many of the terms currently used demean the humanity and natural condition of having a disability. Certain terms are demeaning and create an invisible barrier to inclusion as equal community members.”

One example of demeaning language when referring to a person with a disability is the term “mentally retarded”. Preferred or respectful language instead is “a person with an intellectual disability.” The person always comes first when using respectful language, and the disability is mentioned second. We are people first, and our disabilities come second.

“If it was not for the hard working Arkansas People First Advocacy and Public Education Committees, Executive Board officers, and chapter members who showed up to the support the bill, this milestone could not have been accomplished,” Eric Treat, Arkansas People First State president commented.

Our congratulations go to the State of Arkansas for becoming the sixth state in the nation to pass a respectful language bill into law.

then the definition may change; if the definition changes, the criteria may change; and if the criteria change, then some people who need services may no longer be able to receive them.

"It seems likely to me that the term mental retardation will increasingly fall out of favor, and perhaps out of common usage," says Steven Warren, former President of AAIDD—when it was still AAMR—and part of their Language Task Force. "More likely, [it] will be replaced by an array of different terms. In the meantime, perhaps we should intentionally keep this term alive in our laws and diagnostic manuals to assure that appropriate services are provided to individuals who, by any name, will surely continue to need meaningful supports to enjoy the quality of life possible in a truly inclusive society."

However, most people do not see denial of services as being under threat, compared to the self-worth and empowerment of individuals with disabilities. "Perceptions can be very damaging," adds Mr. Martagnetti. "Removing the title [mentally retarded] can be very helpful in removing the [negative] perceptions surrounding those people."

On both sides of the name debate, the power of language is the common denominator. While keeping language that is negatively charged has far reaching implications for the identity of many individuals with disabilities, a change in terminology could bring formidable consequences for the efficiency and provision of needed services for those individuals.

Language is a primary transmitter of the values and perspectives of a culture. When talking about an individual or group of people, words are not just identifiers. They also project a set of meanings onto the subject. A possible far-reaching change in the language about people with disabilities may change not only what is being said, but what is being thought and done as well. "If the medical and scientific world adopts new terminology, I believe it could lead the way to create new and more positive perspectives on intellectual disabilities," says Carol Greenwald, president of the Board of ArcTN. "However, I also believe that positive changes in public views on disability can lead to changes in language. So change is not just one way."

The future of the term "retardation" and related terminology may still be unclear, and the tides may not shift overnight. But one pressing responsibility we have is to be responsible stewards of our culture when it comes to what we say and how we talk about others.

Furthermore, we need not be afraid to think critically; the right questions can lead to answers that may offer interesting insights. Self-advocate Liz Weintraub, quality enhancement specialist for the Council on Quality and Leadership, offers an historical example that poses such a question. "African-Americans asked people in the 60s to stop calling them 'the N word', and [people listened].

Why can't people without developmental disabilities listen when we say, 'Stop calling us the R word'?"

Linking history to the present could make the case even stronger. Perhaps we should start to examine how our culture identifies someone who is "normally mentally developed" versus someone who has an intellectual or cognitive disability. Beyond that, who has the authority to define normalcy in the first place?

We are fortunate to have a nearly limitless vocabulary to apply to our world and the people in it. Ultimately, whether posing questions or solutions, we need to choose a way of talking about all individuals that will enable them to best and most clearly speak for themselves in an ever growing and changing cultural and social climate. We need to think culturally, speak carefully. After all, there does seem to be a lot in a name.

*Beth Hopkins is a Youth Leadership Forum graduate and is currently an intern with the Council on Developmental Disabilities.*

## TENNESSEE DISABILITY MEGACONFERENCE

### When?

May 31 – June 2, 2007

### Where?

Nashville Airport Marriott

### Why?

Workshops and interactive sessions on a variety of disability-related topics presented by local and national speakers including:

Sue Thomas • Lois Curtis • Glenda Horton-Manning  
• Sujeet Desai • Robert Watson • Light Motion •  
Tim Picarillo • Sue Swenson • Eddie Tuduri and the  
Rhythmic Arts Project • Erin Brady Worsham

### How?

For more information including registration forms please visit the conference Web site at:

**[www.tndisabilitymegaconference.org](http://www.tndisabilitymegaconference.org)  
or call 615-298-1080 ext 26**

- EVENING ENTERTAINMENT •
- NETWORKING OPPORTUNITIES •
- INFORMATIVE EXHIBITS •



## WHY ARE WE COMBATING OUR KIDS?

COMMENTARY BY GINA LYNETTE

Oh, son, I am so, so sorry...

*From the press release announcing the passage of the "Combating Autism Act":*

"This bill is a federal declaration of war on the epidemic of autism," said Jon Shestack, co-founder of Cure Autism Now. "It creates a congressionally mandated roadmap for a federal assault on autism, including requirements for strategic planning, budget transparency, Congressional oversight, and a substantial role for parents of children with autism in the federal decision-making process."

"By passing this landmark single-disease legislation, the House has recognized the daily plight of the thousands of families struggling every day with autism, and has once and for all acknowledged autism as a national healthcare crisis," said Bob Wright, co-founder of Autism Speaks and chairman and CEO of NBC Universal.

The name of the act alone sent me into a rage, but this? War on the epidemic of autism. Assault on autism. Daily plight. Families struggling. Once and for all acknowledged autism as a national healthcare crisis. All of this packed into two sentences! And this



Gina and Bernie Lynette

stuff was said by family members of children with autism... not professionals or lobbyists.

These people are declaring war on my son, and their own children! They just don't get it, do they?

I just want to go on the record saying that, while I am all for finding accommodations that help folks participate in the world, offering medical treatment to those who need it, finding new ways to make people more aware, and the like—I am not cool with using the same language we apply to terrorists and drug lords for legislation regarding our sons and daughters.

## BUILDING ON THE METAPHOR

COMMENTARY BY TINA MARASCIA

While speaking to a very intelligent individual regarding inclusive school environments, I was distressed by a metaphor he used. I didn't, at the time, understand my irritation but have since come to understand my anxiety. As a rebuttal to inclusive programming, this person told me, "Tina, I love my vehicle, but I wouldn't try to race it in the Indy 500. It just couldn't keep up." With no perfect response on my tongue—only fire, and a knot in my stomach—I decided to ponder this a bit before replying.

His statement bothered me for quite a while, for so many reasons. First of all, does a vehicle care if it spends its life in a garage or races in the Indy 500? Of course not! We aren't talking about a thing, but a person—a person who may just want to run that race. And if a person wants to run a race, let them run the race!

If there are 40 racers, how many are going to win? One, three, or maybe five? That leaves 35 racers who couldn't "keep up." Should they have stayed home? Should we inform them that they're not going to have a chance at winning, so they should just stay home? Of course not!

In everything there are winners and losers. There is a beginning and an end. There will always be the fastest and the slowest. There

is first and last place. Yet, all of this doesn't determine the love of a sport. Joy is in the doing. Accomplishment is in the very act of trying. Self-determination is about making choices that make us happy. Why should we be limited by the level of someone else's abilities? We should only be limited by our personal limitations, and only then when they are real.

After all, what are we trying to put out there? Should we expect that only the best at any activity be allowed to participate? I don't think so. What if we really aren't any good at what we love to do? Should we stop doing it?

Why does everyone always have to keep up? This infuriates, annoys and frustrates me. Nobody on this great green earth has the ability to keep up with everyone, in every area. Does that mean we aren't allowed to participate at all?

I don't try to "keep up" with the Jones's with their million dollar homes. I don't try to "keep up" with my neighbors with their cars and clothes. I don't try to "keep up" with anyone. I live my life according to my own priorities, with no desire to "keep up" with anyone or anything.

Everyone is born into this society. Everyone has the right to participate in any activity they want to participate in within our

Since when do we wage war on children? It is not okay to forget that my children are just that—children.

The language we use is important! How often do individuals with diagnoses hear that there is “something wrong with them”? How many times can they hear that without believing it? Unfortunately, other people believe it too. So, for the record, there is nothing “wrong” with my children. They are not the cause of some “daily plight” in my life. We get along just fine, thank you very much.

I know that there are plenty of folks ready to heap ashes on my head for thinking this way. They will point to their own kids and say, “Look at my child. He bangs his head. He drools. He spreads poop on the walls. He has behaviors. You just don’t understand!”

I do understand. I have seen it all. I have lived it all. And still I refuse to blame my children and lay the burden of my lack of happiness at their feet. I will not “wage war” on them. I will love them and care for them and stick up for them and educate them and tell them over and over again that they are awesome.

Because they are.

*Gina Lynette is a Partners graduate (2003–04) and lives in Knoxville*

society. If there is a need for support or tools to make it possible, then get it, or provide it. If a person cannot draw to save his life but wants to draw, how dare we say he can’t?

Few will choose to do anything that is too frustrating, so why do we have to be the ones to say “don’t”, or “you can’t”? If we tell them they can...who knows how they may surprise us, or themselves?

*Tina Marascia is a member of the current Partners class and the mother of a child with an autism spectrum disorder*



Left to right: Alexandria, Rob, Robbie, Tina and Tommy Marascia

## TWO INTERNS AT WORK ON COUNCIL PROJECTS

BY WANDA WILLIS

The Council awarded internships to two individuals who are working on a variety of projects in the Council office. The internships began in February and will continue through May 2007.



Angela Bechtel

**Angela Bechtel** is a second-year graduate student at the University of Tennessee, College of Social Work in Nashville. She is working with the Council public policy director on several research projects and attending relevant legislative committee meetings at the General Assembly. Ms. Bechtel also is a member of the 2006–07 Partners in Policymaking™ class, and the parent of three daughters, ages 13, 11, and 8, as well as a 7-year-old son with autism.

“I value and appreciate the opportunity to be a change agent in a field about which I am so passionate,” Ms. Bechtel said. “The Council strives to empower Tennesseans with disabilities and I feel honored and fortunate to be part of that mission.”



Beth Hopkins

**Beth Hopkins** is a graduate of Hume-Fogg High School in Nashville, and is a recent graduate of Middle Tennessee State University. She plans to attend the University of Georgia as a graduate student in the Fall. Ms. Hopkins, a graduate of the Council’s Youth Leadership Forum, is working on several projects with the Council Leadership Institute (Partners in Policymaking and the Youth Leadership Forum). She has redesigned brochures for both programs that will be in print this Spring, and has assisted in conducting national surveys for the Council. Ms. Hopkins has cerebral palsy and uses a wheelchair.

“I have truly enjoyed working with the Council so far,” Ms. Hopkins said. “The staff is very positive and supportive, and I am really glad to be able to support such great projects for the benefit of people with disabilities through my work here as an intern.”

The Council intern program began last year with an intern from Auburn University’s Rehabilitation Services Department, Ashley Coulter. Council executive director, Wanda Willis, described the intern program as one of the best endeavors of the Council, both for the Council and for the disability community at large. “Our interns experience first-hand disability public policy work,” said Ms. Willis. “They have opportunities to meet leaders in self-advocacy and advocacy organizations, State and federal government offices, and to take part in problem-solving strategy sessions about complex issues facing our communities and state. However, the greatest beneficiary is the Council. Beth and Angela bring fresh ideas and can-do attitudes to our work.”

Photos of Ms. Bechtel and Ms. Hopkins by Errol L. Elshtain

# OVERWEIGHT PREVENTION FOR CHILDREN WITH DISABILITIES AND OTHER HEALTH CARE NEEDS

BY COURTNEY EVANS

Research suggests that, if current trends continue, by the year 2010 close to 50% of all children worldwide will be overweight.

This staggering figure is due in part to the high caloric intake/low activity lifestyles of many children and families. The complicated factors influencing the state of being overweight or obese become even more complex for children with disabilities and other health care needs.

## Addressing the Issue

On March 8–9, 2007, the University of Tennessee Boling Center for Developmental Disabilities, in collaboration with the Atlantic Coast Consortium of University Centers for Excellence in Developmental Disabilities, presented a live video conference, “Overweight Prevention for Children with Special Health Care Needs.” The conference was broadcast to eight remote sites across the country, including two in Tennessee: the University of Tennessee (Knoxville) and the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (Nashville). The two-day conference focused on causes, effects, and prevention techniques related to obesity in children with disabilities and other health care needs, with the target audience being families and service providers.

## Possible Causes of Weight Gain

While being overweight or obese is often related to diet and exercise, children with disabilities and other health care needs must also grapple with treatment side effects that further contribute to weight gain. For example, in some instances, the weight increase seen in children may be caused by the medicine(s) they are taking. Many common medications prescribed to children with disabilities are known to promote weight gain by increasing the appetite and slowing down the metabolism. Several antipsychotic drugs often given to patients with bipolar disorder, schizophrenia, and autism can cause as much as a 7% increase in body weight. In addition, many antidepressants, antihistamines, and mood stabilizers that also promote weight gain may be prescribed in conjunction with antipsychotics, thus doubling the risk.

Several other possible causes of weight gain are somewhat unique to these children. First are the food-reward systems for positive behaviors in place in many therapeutic and school settings. Second, oral-motor problems that might determine food types can adversely influence food intake. Finally, a child’s inability to accurately indicate satiety may contribute to excessive weight gain. Aida Miles, RD, CSP, LD, CNSD, a pediatric dietician and consultant with The Marcus Institute, noted, in her presentation on nutrition assessment, that in some instances eating may be a “method of



counteracting frustration for a child with special needs, because it is something they can do by themselves and do well.”

Obesity is associated with a number of negative effects on the health and well-being of a child. Metabolic issues, such as Type 2 diabetes, accelerated bone age, and early puberty can occur. Cardiac problems include hypertension, heart failure, and stroke. Pulmonary problems include obstructive sleep apnea, hypoventilation, and asthma. Neuropsychiatric conditions such as depression and anxiety, or bullying and social isolation can add to the emotional discomfort of a child with a disability.

## Prevention Techniques

What can one do to encourage the prevention of obesity in children? George A. Burghen, MD, Professor of Pediatrics and Chief of the Division of Endocrinology and Metabolism at the University of Tennessee at Memphis, told the conference participants that it takes a team to effectively approach the problem. Dr. Burghen suggested that families can help by sitting down and “eating dinner with children, creating a ‘sacred space,’” rather than rushing through a distracted meal in front of the television. He noted that it is important to educate parents about nutritional guidelines and encourage them to incorporate them in daily meal planning. Dr. Burghen further urged parents to demand that schools provide healthier items for vending machines and emphasized the need for people to limit processed and fast foods to no more than once a week.

Dr. Burghen also spoke about the responsibility that primary care physicians have to the families they serve to provide weight evaluations and information on overweight prevention for at-risk patients. All of the presenters at the conference agreed that weight is a sensitive topic for many people, and that physicians must handle the subject with care. However, they also agreed that the issue must be addressed proactively.

S. Casey Laizure, Associate Professor of Pharmacology at the University of Tennessee at Memphis, spoke on the topic of avoiding drug-induced weight gain. He suggested that, short of avoiding these drugs altogether, one might consult with the prescribing



physician about the possibility of ordering the lowest possible dose of the medication. He also mentioned that, albeit not ideal, some drugs work to counteract the weight gain component of other drugs. However, diet and exercise were mentioned as the best way to combat the effects of medications that cause or contribute to weight gain.

"We cannot predict who will be susceptible to drug-induced weight gain," Dr. Laizure said. "The weight increase is due to increased caloric consumption caused by the increased appetite. The real fix is maintaining a good diet and regular exercise. It's the same old story. These actions will help reduce the risk."

"Exercise is known to promote better healing, to produce feelings of euphoria, to improve short-term awareness and cognition, and to improve sleeping patterns," said James H. Rimmer, PhD, Director of the National Center on Physical Activity and Disability (NCPAD). "Participation in play, recreation, and sport has a major effect on overall growth and development and all are critical elements for a satisfying childhood and adolescence."

Dr. Rimmer's Center addresses the barriers that may prevent children with disabilities and other health care needs from reaching their full exercising potential. One of the goals of NCPAD is to encourage and educate exercise facilitators to customize physical activities for individual needs and skill levels. A number of adaptive equipment systems are available. In fact, many everyday sports have been adapted to meet disability-specific abilities. NCPAD aims to connect people with these resources. "The resources for overweight prevention for kids with special needs are out there," said Dr. Rimmer. "You just have to know how to connect to them."

*Courtney Evans is communications coordinator, Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities Education, Research and Service.*

### Helpful Links

*Programs on Weight Management for Children*

Kid Shape: [www.kidshape.com](http://www.kidshape.com)

Way To Go Kids: [www.waytogokids.com](http://www.waytogokids.com)

*Physical Activity*

National Center on Physical Activity and Disability

[www.ncpad.org](http://www.ncpad.org)

*Nutrition*

Nutrition Navigator: <http://navigator.tufts.edu>

USDA's Food and Nutrition Information Center

[www.nal.usda.gov/fnic](http://www.nal.usda.gov/fnic)

*Resources for Service Providers*

American Dietetic Association: [www.eatright.org](http://www.eatright.org)

Bright Futures: [www.brightfutures.org](http://www.brightfutures.org)

## TENNESSEE SPOTLIGHT

**Partners graduate Pam Bryan** has been asked to serve on the American Trauma Society's new Trauma Survivors Advisory Council. This is a national council, whose first meeting was held in March in Washington, D.C. Ms. Bryan was recommended by Dr. Morris, director of Trauma and Surgical Critical Care at Vanderbilt. In addition, Ms. Bryan is working closely with Dr. Morris to start an Advisory Council for the Vanderbilt Trauma Unit.

**Lizzy B Solomon, daughter of Council staff member, Ned Andrew Solomon, and Partners graduate, Amy Harris-Solomon**, recently won an award from The 2007 Yes I Can! International Awards Program. Ms. Solomon was nominated by Kevin Casey, president of Exceptional Co., a company that has selected Ms. Solomon's greeting card company, Lizzy's Lines, as their 1st Exceptional Feature. Letters of recommendation were sent by Terri Chapman, C.E.O. Academy, Inc., and Nina Harris, special educator and friend. Ms. Solomon won in the category of extracurricular activities.

The Yes I Can! International Awards Program was established in 1981 to celebrate the achievements of children and youth with disabilities; to encourage children and youth with disabilities to seek their highest potential; and to increase public awareness of the abilities, aspirations, and personal qualities of people with disabilities. Ms. Solomon was invited to attend a special awards ceremony held in conjunction with the Council for Exceptional Children's Annual Convention & Expo in April in Louisville, Kentucky.

### And from the Youth Leadership Forum graduate files...

**Beth Hopkins** will be enrolled in the MNPO (Master's in Non-Profit Organizations) program through the School of Social Work at the University of Georgia (UGA) in Athens, Georgia. It is a two-year interdisciplinary program with six core courses, two internships, and a variety of electives to be chosen according to Ms. Hopkins' individual interests.

**Brittany Carter** spent last semester at the University of Edinburgh and is currently in Athens, Greece. In addition to her studies, she is volunteering at the Greek Therapeutic Equestrian Center working with 4-8 year-olds. Ms. Carter has established several support activities for local youth with diabetes, and has taught in community service workshops on the subject of managing diabetes as a teen. She has been featured in the JDRF International Diabetes Youth Magazine and in many newspaper articles, and has been interviewed on television and radio for her work with diabetic youth.

Her scholarships include Discover Card, Presidential Freedom, Prudential, Elks MVS-National, Coca-Cola, Hitachi Foundation's Yoshiyama Award and a local scholarship from the Niswonger Foundation. Many of the scholarships have offered either one-time or continuous leadership training. As a college junior, Ms. Carter, who has cerebral palsy, is beginning to think about advocacy law as a career, and will be working for an advocacy attorney this Summer.

## **SUMMER PROGRAMS** provide children and young adults with opportunities for learning, socialization, and having fun.

From day to residential programs and arts to sports, there are a variety of camps available for people of all abilities. The following resources can help families find a program that meets the camper's interests and needs.

Inclusive camps serve campers with and without disabilities. For example, Nashville's Adventure Science Center offers a series of Summer camps for children entering kindergarten through eighth grade. Campers explore different scientific experiments and themes each week; 2007 topics include animals, space, robots, "The Science of Music" and more. The Center provides inclusivity by handling each camper's needs on an individual basis.

Before camp begins, camp coordinators meet with the prospective campers' parents to discuss the best care for their children.

The National Center on Accessibility's Discover Camp project encourages such camp visits, which allow caregivers to determine the program's philosophy toward including all children in activities. Discover Camp, a collaborative project dedicated to the inclusion of children with disabilities and chronic illnesses in recreational opportunities, provides these suggestions for selecting a camp for a person with a disability:

- \* Visit the camp and talk with the camp director to discover the philosophy of the camp, especially if your child has a disability. What is their approach in including all children in activities?
- \* Know the staff to camper ratio.
- \* Learn about the ways staff are trained and the policies that guide their behavior. Understand the standards that the camp must follow. Many camps are endorsed and certified by the American Camping Association. The ACA annually publishes a parents' guide to accredited camps ... a good place to start. Visit their Web site at [www.ACAcamps.org](http://www.ACAcamps.org).
- \* What activities are offered? How will your child be included in those activities? Assess the accessibility of facilities.
- \* What type of medical support is provided at camp?
- \* What are the appropriate ways to communicate to staff to get progress reports on your child?

One East Tennessee camp included a child with cerebral palsy by providing accessible transportation and a support professional. With advance planning, flexibility, and creativity, camp programs and families can work together to ensure a successful camp experience for campers of all abilities.

Some families find that specialty camps, or camps serving a specific population, are more appropriate for their campers. Examples of specialty camps include those offered by the League for the Deaf and Hard of Hearing (LDHH) and the Down Syndrome Association of Middle Tennessee (DSAMT).



BY MELISSA FORTSON

LDHH's Stepping Stones, a Summer day program for 8–14 year-olds who are deaf or hard-of-hearing, focuses on reading, writing, Deaf Culture, drama and extracurricular activities. DSAMT's My Life, My Choice, My Plan (MMM) provides young adults with Down syndrome the opportunity to have fun, learn, make friends, and gain independence. Both camps allow campers to meet peers who have similar disabilities; specialty camps also provide teaching opportunities specific to a particular disability or health condition.

Camp Smile, a day camp in Collierville, is a place for youth with developmental disabilities to enjoy arts, recreation, field trips, theme days, and more. This popular camp, offered by the Collierville Parks, Recreation, and Cultural Arts Department, is representative of the many Summer opportunities offered by community parks and recreation departments. Cathy Rader, specialized skills supervisor with the Metropolitan Nashville Board of Parks and Recreation, recently spoke with a group of individuals with intellectual disabilities and their families about daily recreational activities available through the city's parks department, including sports, music, art, bowling, swimming, and other activities. Both the City of Chattanooga and Williamson County offer therapeutic recreation programs which provide leisure and recreation opportunities for people of all ages and abilities.

Schools and universities also offer ideas and opportunities for Summer recreation. As part of its Interdisciplinary Leadership Training Series, the Boling Center for Developmental Disabilities recently offered a session on "Summer Ideas and Fun." The Center also sponsors the All Days Are Happy Days Summer Camp, a week-long camp for children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD).

The Vanderbilt Kennedy Center for Excellence in Developmental Disabilities co-hosts several Summer programs, including camps for students with autism, developmental disabilities, or Down syndrome. The Center's third annual music camp for young adults with Williams syndrome focuses on social skills and independence

and allows campers to celebrate music by participating in a songwriting workshop, recording session, songwriter's night and a live performance on the stage of the Grand Ole Opry.

As the Summer camp season approaches, many families are beginning the search for recreational activities. From choosing what kind of camp is best—inclusive, specialty, art, outdoor adventure, science, etc.—to knowing what kinds of questions

to ask, there is much to consider. There are resources to help families find programs that will meet their needs. Please see the information provided below for good places to start looking!

*Melissa Fortson is an information & referral specialist/program coordinator with Tennessee Disability Pathfinder, a joint project of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy Center UCEDD.*

## ✧ SUMMER PROGRAM RESOURCES

The following organizations provide general information regarding camps and people with disabilities as well as listings of specific Summer programs. There are additional opportunities not listed in these directories. Check with other parents, teachers, parks and recreation departments, religious organizations, or community groups to see what is available where you live.

Tennessee Disability Pathfinder provides information regarding camps with disability or specialty programs available.

Call 800-640-4636 or visit [www.familypathfinder.org](http://www.familypathfinder.org) (click on "Recreation and Summer Camps").

Discover Camp is a resource for parents of children with disabilities selecting a camp for their child.

<http://ncaonline.org/discover/>

The Family Village Recreation and Leisure Center provides information regarding camps and adaptive recreational opportunities. <http://www.familyvillage.wisc.edu/> (click on "Recreation and Leisure").

The Junior League Family Resource Center at Vanderbilt Children's Hospital has an online Camp Directory, which provides information on Summer programs for children with chronic illnesses and disabilities. Many of the programs listed are in the Middle Tennessee region; national camps serving children with chronic conditions are included for some specific conditions. The Web site also includes tips on choosing the right camp for people of all abilities. Call 800-288-0391 or visit <http://www.vanderbiltchildrens.com> (click on "Family Resources").

The National Center on Accessibility promotes inclusive recreation opportunities for people of all abilities. <http://ncaonline.org/>

The National Dissemination Center for Children and Youth with Disabilities (NICHCY) offers a listing of campsites and programs around the nation that offer services and specialized Summer camp programs for children and youth with disabilities. <http://www.nichcy.org/pubs/genresc/camps.htm>

Contact information for programs mentioned in the article is listed in the next column.

## ✧ ✧ ✧ ✧ ✧ ✧ ✧ ✧

Adventure Science Center

John Hawkins, camp coordinator

615-862-5117 or [info@adventuresci.com](mailto:info@adventuresci.com)

<http://www.adventuresci.com/>

Boling Center for Developmental Disabilities

901-448-6511 or 888-572-2249

<http://www.utmem.edu/bcdd/>

Camp Smile (Collierville Parks, Recreation, and Cultural Arts Department)

Lisa Gaither, camp director

901-853-3225 or [lgaither@ci.collierville.tn.us](mailto:lgaither@ci.collierville.tn.us)

<http://www.colliervilleparks.org/>

City of Chattanooga Therapeutic Recreation

Lizzy Hockinson, therapeutic recreation specialist

423.643.5716 or [hockinson\\_l@mail.chattanooga.gov](mailto:hockinson_l@mail.chattanooga.gov)

<http://www.chattanooga.gov/>

Down Syndrome Association of Middle Tennessee

Sheila Moore, executive director

615-386-9002 or [dsamt@bellsouth.net](mailto:dsamt@bellsouth.net)

<http://www.dsamt.org/>

League for the Deaf and Hard of Hearing

Brigette Ochoa, youth director

615-248-8828 (V/TTY) or [bo@ldhh.org](mailto:bo@ldhh.org)

<http://www.ldhh.org>

Metro Board of Parks and Recreation (Nashville)

Cathy Rader, Metro Parks Disabilities Program

615-862-8479 or [cathy.rader@nashville.gov](mailto:cathy.rader@nashville.gov)

<http://www.nashville.gov/parks/>

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

Gretchen Herbert, recreation & art coordinator

615-322-8147 ext. 14 or [gretchen.herbert@vanderbilt.edu](mailto:gretchen.herbert@vanderbilt.edu)

<http://www.kc.vanderbilt.edu>

Williamson County Parks and Recreation

Vicky Pitner, therapeutic administrator

615-790-5719 or [vickyp@williamson-tn.org](mailto:vickyp@williamson-tn.org)

<http://www.williamsoncounty-tn.gov>



# GOVERNOR APPOINTS NEW COUNCIL MEMBERS

All photos by Errol L. Elstain

Governor Bredesen recently made four appointments to the Council on Developmental Disabilities and *Breaking Ground* is pleased to introduce them.



**George Dylan Brown** lives in Hendersonville and is an At-Large representative on the Council. In addition to being a Partners in Policymaking™ graduate (2003–04), Mr. Brown served a Congressional internship during the Summer of 2004. Working in Senator Bill Frist's office for six weeks and then in Congressman Roy Blount's office for six weeks gave Mr. Brown a great

understanding of how Congress works on a daily basis.

"I am very pleased that I was selected to serve on the Tennessee Council on Developmental Disabilities. I hope that my experience as young man who has spent the previous five years living with a spinal cord injury serves the Council well. I look forward to using my experiences with regards to nursing and personal assistance, how to work with vocational rehabilitation services to assist with college, and most importantly help push for self-determination goals to be met. As a new Council member, I look forward to learning more about the many issues that affect people with disabilities and finding as many solutions to these problems as possible."



**Katherine A.T. Watson** is one of two representatives of the Southeast Development District on the Council.

"I am veterinarian and have worked at Ashland Terrace Animal Hospital in Chattanooga for 21 years. With the birth of my second son, I cut my hours at Ashland Terrace and started a

home business, Sale Creek Veterinary Services, and work mainly with goats and small ruminants. I have two children, Brian, 16, and Allen, 4. Brian has Spina Bifida and Hydrocephalus. We are involved in SPARC (SPorts, Arts, and Recreation of Chattanooga), which is a local group that provides recreational opportunities for children and adults with disabilities. I am very active in North River Christian Church and publish a weekly newsletter for our members. At home I have a small Goat Dairy with an average of 10 milking does. We make cheese and soaps. My wonderful husband Keith is an engineer for General Electric."

Dr. Watson hopes to bring energy and the perspective of her experiences to the Council.



**Heather M. Wilson** graduated Partners in Policymaking™ in 2003 and returned as a speaker to the Class of 2005–06. Ms. Wilson lives in Loudon, near Knoxville, and represents the East Tennessee Development District. She has a Bachelor of Arts degree in general psychology from the University of Tennessee, Knoxville.

"As an individual with a disability, I have worked hard to overcome the limiting perceptions of individuals and systems I have encountered in my education and, more recently, in my efforts to find gainful, meaningful employment."

Ms. Wilson uses a power wheelchair and says she takes pride in the fact that she "never takes the easy way out unless the easy way is the best way," adding, "...a positive attitude plays a crucial role when there are changes to be made." She strives to be independent in her life and wants to bring her knowledge and solutions to the challenges people with disabilities face while trying to become gainfully employed.

Ms. Wilson brings to the Council her "commitment to see to it that people with disabilities not only have equal opportunities but also have equal choices in life. In particular, I am referring to the current dilemmas regarding...personal care assistance programs. I have first hand knowledge that for some, an aging family member is indeed the only option for these necessary services."



**Jill Hindman** is a graduate of the inaugural Partners in Policymaking™ class in 1993–94 and represents the Southeast Development District on the Council.

"I was born with Spina Bifida and have used a wheelchair my entire life. I have worked in the disability arena for over 25 years. I

have served as a member of the Chattanooga Area Regional Transportation Authority for 13 years and am a member of the Mayor's Council on Disability for the City of Chattanooga.

"I have a number of issues which I would like to address as a member of the Tennessee Council on Developmental Disabilities. The first area of concern is changing the stigma attached to those of us with disabilities; second is employment of people with disabilities; and, lastly, the creation of more affordable, safe, and accessible housing."

In addition to these new appointments, Governor Bredesen reappointed **Pamela Huber** of Kingsport, representing the First Tennessee Development District, and **Nancy Hardin** of Dyersburg, representing the Northwest Tennessee Development District.

## INTRODUCING THE COUNCIL'S NEW EXECUTIVE COMMITTEE

Governor Bredesen appointed a new Chair and a new Vice-Chair to the Council on Developmental Disabilities. Moving from her previous position as Vice-Chair, Joyce Elaine Sievers, of Smithville, is now Chair of the Council and Steven Sheegog, of Memphis, is now Vice-Chair.



Rear (left to right) Joyce Sievers, Richard Moore, Angela Hazlehurst and Steven Sheegog. Front (left to right) Barron Garrett, Council Member from McMinnville, and Stephanie Cook. Photo by Errol L. Elshtain.

Ms. Sievers, parent of an adult daughter with an intellectual disability, represents the Upper Cumberland Development District on the Council and brings not only her personal experience as a parent to the position, but also her experience as a Family Support coordinator. She is a graduate of the inaugural Partners class.

Mr. Sheegog is the parent of a young man with an autism spectrum disorder and a Partners graduate (1996-97). He represents the Memphis-Delta Development District.

Stephanie Brewer Cook is the new Chair of the Council's Legislative and Public Policy Committee. Ms. Cook uses a wheelchair and represents the East Tennessee Development District.

Angela Hazlehurst agreed to Chair the Council's Project Review Committee. Ms. Hazlehurst is the mother of a young boy with an autism spectrum disorder and represents the Northwest Tennessee Development District.

Richard Moore continues as Chair of the Planning and Priorities Committee of the Council. Mr. Moore represents the Mid-Cumberland Development District and is the father of two children. His son, Matthew, has Down syndrome.



## TENNESSEE DISABILITY PATHFINDER 2007-2008 DIRECTORY ORDER FORM

The **2007-2008 Disability Services & Supports Directory** is published by Tennessee Disability Pathfinder. It is a source of information regarding state and local programs and services. The manual provides detailed information about each agency, including contact information, address, email, Web site, keyword service categories with program descriptions, counties served, non-English speaking staff availability, and office accessibility. It is offered in East, Middle, and West regional editions for \$25 each.

Your order will be shipped, with an invoice, as soon as directories are available. It is important to place your directory order as soon as possible because we are printing based on advance orders. If you have any questions, email Ashley Coulter at [ashley.coulter@vanderbilt.edu](mailto:ashley.coulter@vanderbilt.edu).



	East	Middle	West	Total Amount Due
2007-2008 Disability Services & Supports Directory (\$25 each)				@ \$25 each = \$ .00
				(Quantity of each version)

Name.....  
 Company.....  
 Address.....  
 City / State / Zip.....  
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**Payment options will include cash, credit card, or check.**

Detach, enclose in an envelope and send to:

**Tennessee Disability Pathfinder**  
 1114 17th Avenue South, Suite 105  
 Nashville, Tennessee 37212

615-322-8529, ext. 15  
 800-640-4636 (toll-free)

*Tennessee Disability Pathfinder is a project funded by Tennessee Council on Developmental Disabilities and Vanderbilt Kennedy Center for Excellence in Developmental Disabilities.*



## MEMBERSHIP AND STAFF

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Steven Sheegog, Vice Chair

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Stephanie Brewer Cook, Knoxville  
George Dylan Brown, Hendersonville  
Sara S. Ezell, Nashville  
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Nancy Hardin, Dyersburg  
Angela Hazlehurst, Jackson  
Jill Hindman, Chattanooga  
Pamela Huber, Kingsport  
Sue Lovlace, Centerville  
June Mangum, Memphis  
Richard Moore, J.D., Brentwood  
Randy Oliver, Jackson  
John D. Piver, Gray

Debbie Riffle, Humboldt  
Katherine A.T. Watson, Sale Creek  
Heather M. Wilson, Loudon

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### LOCAL NONGOVERNMENTAL AGENCY

Claudia Avila-Lopez, Project Conexión

### COUNCIL STAFF

Wanda Willis, Executive Director  
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Mildred Sparkman, Administrative Secretary  
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Ned Solomon, Director, Partners in Policymaking™  
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JoEllen Fowler, Administrative Assistant

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